

Extracorporeal membrane oxygenation in children

**Understanding NICE guidance –
information for children and parents or
carers considering the procedure, and for
the public**

January 2004

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About this information

This information describes the guidance that the National Institute for Clinical Excellence (NICE) has issued to the NHS on a procedure called extracorporeal membrane oxygenation. It is not a complete description of what is involved in the procedure – the patient's healthcare team should describe it in detail.

NICE has looked at whether extracorporeal membrane oxygenation is safe enough and works well enough for it to be used routinely for the treatment of children with severe cardiac or respiratory failure.

To produce this guidance, NICE has:

- looked at the results of studies on the safety of extracorporeal membrane oxygenation and how well it works
- asked experts for their opinion
- asked the views of the organisations that speak for the healthcare professionals and the patients and carers who will be affected by this guidance.

This guidance is part of NICE's work on 'interventional procedures' (see 'Further information' on page 10).

About extracorporeal membrane oxygenation

Extracorporeal membrane oxygenation (ECMO) is a temporary life support system used for people whose heart or lungs have stopped working properly. In children, this can be caused by a number of things such as very severe infections, heart conditions, severe burns, or bleeding from the lungs. ECMO is used for children who are very seriously ill and who have not responded to other measures. It can also be used for children whose hearts have been artificially stopped during heart surgery, to help take the strain off their system after the operation.

The ECMO machine does the work of the child's heart and/or lungs. A tube carries blood from the right side of the heart, which is then pumped through an artificial lung where it picks up oxygen. This oxygen-rich blood is then passed back into the child's blood system. A drug is given to stop the blood from clotting.

How well it works

What the studies said

The studies NICE looked at showed that ECMO worked well for children with heart and/or lung failure. The largest study showed that ECMO was successful for over half (57%) of the children who had it.

What the experts said

The experts agreed that the benefits of ECMO were proven.

Risks and possible problems

What the studies said

The most common problems associated with ECMO were bleeding and kidney failure, which occurred in about half of the children who had the procedure. Some children also suffered fits or a problem known as haemolysis where blood cells break down, but these were less common.

What the experts said

The experts decided that infections, bleeding, nerve damage and problems with the ECMO machinery were possible complications with this procedure but that these were not common. They also noted that the procedure was well established in a small number of hospitals where it was performed by highly trained staff.

What has NICE decided?

NICE has considered the evidence on extracorporeal membrane oxygenation. It has recommended that when doctors use it for children with cardiac or respiratory failure, they should be sure that:

- you or your child understands what is involved and agrees (consents) to the treatment, and
- the results of the procedure are monitored.

There should also be special arrangements for monitoring what happens when a child has ECMO. NICE is asking doctors to send information about every patient who has the operation and what happens to them afterwards to a central store of information at the international registry of the Extracorporeal Life Support Organisation (ELSO). This will mean that the safety of the procedure and how well it works can be checked over time.

A study is in progress comparing a conventional life support technique with ECMO in adults and this should provide additional evidence about the use of the procedure.

What the decision means for you

Your doctor may have offered you or your child ECMO. NICE has considered this procedure because it is relatively new. NICE has decided that the procedure is safe enough and works well enough for use in the NHS. Nonetheless, you should understand the benefits and risks of ECMO before you agree to it. Your doctor should discuss the benefits and risks with you. Some of these benefits and risks may be described above.

NICE has also decided that more information is needed about ECMO. So NICE has recommended that some details should be collected about every patient who has this procedure in England and Wales. These details will be held confidentially and will not include patients' names. The information will be used only to see how safe the procedure is and how well it works. If you decide to have ECMO, you will be asked to agree to your details being entered into an electronic database for this purpose. A clinician looking after you or your child will fully explain the purpose of collecting the data and what details will be held. You will be asked to sign a consent form. If you do not agree to the details being entered into an electronic database, you or your child will still be allowed to have the procedure.

Further information

You have the right to be fully informed and to share in decision-making about the treatment you or your child receives. You may want to discuss this guidance with the doctors and nurses looking after you.

You can visit the NICE website (www.nice.org.uk) for further information about the National Institute for Clinical Excellence and the Interventional Procedures Programme. A copy of the full guidance on ECMO in children is on the NICE website (www.nice.org.uk/IPG038guidance), or you can order a copy from the website or by telephoning the NHS Response Line on 0870 1555 455 and quoting reference number N0421. The evidence that NICE considered in developing this guidance is also available from the NICE website.

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